

***FOCUS GROUPS
WITH
ULCER PATIENTS***

H. PYLORI AWARENESS AND TREATMENT

REPORT OF FINDINGS AND RECOMMENDATIONS

Presented to:

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Executive Summary

Purpose of the Study

On behalf of the National Center for Infectious Diseases of the U.S. Centers for Disease Control and Prevention, Westat conducted 12 focus groups with consumers who identified themselves as having been diagnosed with an ulcer or having suspected that they have an ulcer. The objectives of the group were to profile:

- How ulcers affect patients' lives;
- What a cure would mean;
- Awareness of the association of the bacterium (*H. pylori*) with ulcer disease; and
- Response to four creative concepts for communicating information about the cause of most ulcers (*H. pylori*) and treatment for it.

Background

Twelve groups were conducted in five cities with people who had either been diagnosed by a physician as having ulcers or who personally suspected that they did. To reflect CDC data about the age and income of most ulcer sufferers, all participants were over age 35 and a majority were from households with incomes under \$35K. Four groups each were conducted with non-Hispanic white consumers, African American consumers, and Hispanic consumers. The Hispanic groups were conducted in Spanish and the study materials were adapted and translated for presentation to these participants.

Participants for the groups were recruited under Westat's supervision by commercial market research firms in the respective cities where the groups were conducted. All of the sessions were conducted as traditional 2-hour focus groups and were facilitated by professional focus group moderators with substantial experience moderating focus groups on health-related topics. Several people from CDC, Westat, and the creative contractor responsible for development of the concepts observed each group. A bilingual observer provided simulcast translation of the sessions conducted in Spanish for the benefit of the observers who spoke only English.

Summary of Findings

The following findings emerged from the 12 focus groups. They are discussed in more detail in Chapter 2 of this report.

- Life with ulcers involves significant pain for many sufferers as well as inconvenient lifestyle adjustments. Chief among lifestyle effects is changing one's diet to forego foods believed to cause and/or aggravate ulcers, especially spicy foods.

- Life with ulcers requires regular use of medications to relieve symptoms. Almost all participants reported use of common over-the-counter medications such as Tagamet, Zantac, PepcidAC, Tums, Maalox AlkaSeltzer, and Mylanta. Only a few people reported taking any prescription medications for ulcer relief; two of these participants reported being treated with antibiotics.
- Home remedies and homeopathic treatments were mentioned often by the Hispanic participants and sometimes by African American participants. These remedies were seldom mentioned by any non-Hispanic white participants.
- Almost everyone in all the groups thought that ulcers are caused by foods and beverages and/or by stress. They said stress from work, family life, or other pressures causes flare-ups that can only be controlled by avoiding certain foods and using medications and/or home remedies. Only a few people had heard about the *H. pylori* finding before the moderator brought it up. One person thought ulcers were caused by taking too much aspirin.
- A few people had heard or read that a bacterium causes ulcers, including some people who named *H. pylori* when they described what they had heard or read. Almost everyone who knew about the bacterium had learned about it from consumer media, medical literature or the Internet — *not a physician*.
- There were only five participants who said they had been tested for *H. pylori*. Four of these were in the non-Hispanic white groups; the fifth was in a group with Hispanic women. One was treated with “Flagyl and Biaxin” and one with “antibiotics.” Another had just been diagnosed, but no treatment was prescribed yet. Two tested negative for the bacterium.
- Most people were excited to hear that there is now a cure for most ulcers. Life without ulcers would be great: no pain, no medications, and no dietary restrictions. Several people thought they would contact their doctors after learning this information in the focus group. However, several people were very skeptical about the information. *They could not believe it was true if they had not heard about it already from their doctors.*
- “Good News” was chosen by participants in 10 of the 12 groups as either the first choice or as tied for first with another concept. The focus on “cure” in “Good News” was more compelling than the focus on misconceptions about the cause of ulcers featured in “Goodbye Ulcers” and “Not What You Thought.” The uplifting tone was more appealing than “Sadie” and “Eloise.”
- Response to “Good News”: This concept was chosen as “the best” in 8 of the 12 groups and tied for best in 2 others. The prominence of words such as “cure” and the “news” image communicated that there has been an important breakthrough in ulcer treatment. This concept did not tell people to “ask your doctor,” which participants noticed and recommended including. One important concern about this came up in both the African

American and Hispanic groups: many people associated the word “infection” with serious, contagious illnesses and were alarmed by the association between ulcers and “infection.”

- Response to “Goodbye Ulcers, Hello Life”: Participants liked the idea that they could be cured and once again enjoy life in ways that they cannot while contending with ulcers. However, they were sometimes confused about how the visual components—portraying people associated with stress or food—connected to the message. Many of their recommendations about this concept seemed to suggest that they thought the characters were patients, or if not, that the characters should be patients exemplifying how good life could be if they could say goodbye to ulcers.
- Response to “Ulcers: Not What You Thought”: Participants understood the main idea of the concept to be that ulcers are not caused by what they had believed, but there were frequent suggestions to depict examples of what people did associate with ulcers, (i.e., different spicy foods and stressful situations). In addition, participants thought this concept did not focus enough on the fact that there is a cure and that they felt this diminished its appeal and effect.
- Response to “Sadie” / “Eloise”: “Sadie” was the least popular of the English concepts among non-Hispanic white and African American participants. Although some people thought she was amusing and attention getting, there were strong concerns about how her dour expression contradicted the message that there is a cure for ulcers. Participants expected to see someone who has been cured of ulcers looking happy and enjoying life. Some of the Hispanic participants liked “Eloise” and could relate well to her complaining about ulcers, but “Eloise” was seldom chosen as the favorite.
- There was little familiarity with CDC, especially outside Atlanta. However, once it was explained, most people felt that association with CDC would make the information more credible to people.
- Participants in all groups recommended a range of channels, such as print, broadcast, and transit media and print in community locations, for communicating information about *H. pylori* and treatment for it. Specific examples of media and locations varied somewhat between non-Hispanic white, African American, and Hispanic groups. Participants in the Hispanic groups thought it was very important for messages and materials to be in Spanish.

Summary of Conclusions and Recommendations

The findings from these focus groups with ulcer patients suggest the following guidance for CDC decisions about communicating information about *H. pylori*.

1. A creative strategy that focuses on the fact that there is now a cure for ulcers that can relieve the pain and inconvenience of controlling them will be important. The actual cause is of much less interest and importance to people than the fact there is now a cure.

While some reference to the cause will be essential to explaining the availability of a cure, caution is needed to avoid confusion evoked by words such as “infection” and “bacteria.”

2. The “Good News” was chosen by most participants as the “best” overall approach because of its focus on “news” about a “cure.” Emphasizing that the cure is based on *new* information about what really causes ulcers will help to address the potential barrier posed by firm, yet incorrect, beliefs that food and stress cause ulcers.
3. When misconceptions about the cause of ulcers are addressed, it is important to refer to or show specific examples of foods and stressful situations that people blame their ulcers on. Participants in these groups sometimes misunderstood the connection between the people shown in “Goodbye Ulcers” and “Not What You Thought” and their beliefs about the cause of ulcers.
4. Participants exhibited strong interest in seeing people “like themselves” who look as if their ulcers have been cured and they are enjoying life. For example, “Sadie”/ “Eloise” was criticized for portraying the character as if she actually still had an ulcer instead of as she would look—happy—if she was really cured. This desire to see people exemplifying life without ulcers seemed to lead participants to interpret characters shown in “Goodbye Ulcers” and “Not What You Thought” as former or current ulcer sufferers. Many of the suggestions about these two concepts were inconsistent with the fact that the characters were supposed to be examples of people thought to cause stress or fix foods that are mistakenly believed to be causes ulcers: bosses, mothers-in-law, chefs. “Make them look happy” was a frequent recommendation.
5. Prominent use of the phrase “ask your doctor about the cause and cure for ulcers” is advisable for communication strategies. Participants noticed and criticized the absence of “ask your doctor” if it was missing. They wanted people to know that they can get more information and a cure from their physicians.
6. Spanish language materials will be important for communicating messages about *H. pylori* to a significant portion of the Hispanic population according to participants in these groups.
7. Low awareness of CDC calls for more prominent use of the logo with the letters spelled out and perhaps a sentence explaining what CDC is and does. When CDC was explained to participants, its sponsorship of the information was considered an asset and the information was considered more credible than when the same information was mistakenly thought to be from a pharmaceutical firm.
8. Efforts to educate physicians about *H. pylori* in the communication program are vital. People expect to hear information like this from their physicians and were skeptical about

whether it was true because their doctors have not mentioned it.

9. A variety of communication channels other than physicians will also be important given that many people are self-diagnosing and that both physician-diagnosed and self-diagnosed ulcer patients are using over-the-counter medications. Many ulcer patients may hear about this only from non-physician sources, e.g., pharmacists and consumer media. Availability of an 800 number or well-publicized Website with information about the cause and new treatment for ulcers would be a good resource.

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1. Purpose and Background

1.1 Purpose

Until 15 years ago, peptic ulcer disease was thought to be caused by an excess of gastric acid. Despite many drug regimens that decreased this acid, such as antacids, H2 blockers, and proton pump inhibitors, a high recurrence rate of peptic ulcer disease remained. In 1983, the stomach acid theory of peptic ulcer disease was questioned when a bacterium, *H. pylori*, was first recognized to be a cause of peptic ulcer disease and gastric inflammation (gastritis). In 1994, after nearly 10 years of skepticism by the medical community, the National Institutes of Health (NIH) convened a Consensus Development Conference on *H. pylori* to address a variety of questions.

After concluding that *H. pylori* is the major cause of peptic ulcer disease, the Consensus Development Conference recommended that patients with peptic ulcer disease should be evaluated for *H. pylori*, and if infected, treated with microbial agents to eradicate the organism. (*Helicobacter pylori* in *Peptic Ulcer Disease*. NIH Consensus Statement 1994 Feb. 7-9; 12(1):1-22).

Subsequently, the House Committee on Appropriations stated in its Report 104-659 on the FY 1997 budget for the Department of Health and Human Services (DHHS):

“...The Committee is concerned...about whether the *H. pylori* discovery has been adequately disseminated to physicians, other health providers, and patients. Therefore, the Committee has provided sufficient funds for CDC to initiate a trans-departmental public education campaign to foster more effective communication between consumers and physicians on *H. pylori* and its link to ulcer disease...”

Accordingly, Westat, Inc., under contract to the National Center for Infectious Diseases at CDC, has conducted two series of focus groups for planning this important campaign. The first component in the research was an exploration of pharmacists' role in influencing consumer awareness about new health information with treatment implications. While the literature reports on a 1994 study suggesting low awareness among primary care providers of the relationship between *H. pylori* and peptic ulcer disease (A.M. Fendrick. Difference between generalist and specialist physicians regarding *Helicobacter pylori* and peptic ulcer disease. *American Journal of Gastroenterology* 91, no.8, (1996): 1544-1548), there is nothing to inform campaign planners about the potential role pharmacists could play. Accordingly, four focus groups were conducted with retail and chain pharmacists.

This report addresses a second series of focus groups that was conducted with ulcer

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patients to obtain reactions to different creative concepts for communicating information about *H. pylori* as the cause of ulcers and treatment to cure it.

1.2 Discussion Guide

The discussion guide was developed by Westat and revised on the basis of comments from CDC and the creative contractor. The following topics were covered:

- Background explanation for and introduction of participants;
- Life with ulcers and experience with ulcers and ulcer treatment;
- Awareness of the bacterium cause of ulcers;
- General reactions to a series of scientific statements about *H. pylori* and treatment for it;
- Reaction to each of four creative concepts;
- Comparison of the four concepts;
- Reaction to CDC sponsorship; and
- Suggested channels for communicating information on this topic.

1.3 Recruitment, Scheduling and Group Composition

As noted, twelve groups were conducted in five cities with people who had either been diagnosed by a physician as having ulcers or personally suspected that they have an ulcer. To reflect CDC data about the age and income of most ulcer sufferers, all participants were over age 35 and a majority were from households with incomes under \$35K. Four groups each were conducted with non-Hispanic white consumers, African American consumers, and Hispanic consumers. The four Hispanic groups were conducted in Spanish; materials were adapted and translated for presentation to these participants.

Participants for the groups were recruited under Westat's supervision by commercial market research firms in the respective cities where the groups were conducted.

All of the groups were conducted as traditional 2-hour focus groups and were facilitated by professional focus moderators with substantial experience moderating focus groups on health-related topics. Several people from CDC, the contractor to CDC responsible for development of the concepts, and Westat observed each group. The Hispanic groups were conducted in Spanish with simulcast translation by a bilingual observer for the benefit of English-only observers.

The schedule included:

Non-Hispanic white groups:

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- Minneapolis, men and women, ages 55+ (August 13, 1997)
- Minneapolis, men and women, ages 35-54 (August 13, 1997)
- Atlanta, men and women, ages 55+ (August 18, 1997)
- Atlanta, men and women, ages 35-54 (August 18, 1997)

African American groups:

- Atlanta, men and women, ages 55+ (August 19, 1997)
- Atlanta, men and women ages 35-54 (August 19, 1997)
- Baltimore, men and women, ages 55+ (August 20, 1997)
- Baltimore, men and women, ages 35-54 (August 20, 1997)

Hispanic groups:

- Tucson, men, ages 55+ (August 19, 1997)
- Tucson, women, ages 55+ (August 19, 1997)
- Tucson, men, ages 35-54 (August 19, 1997)
- Washington, DC, women, ages 35-54 (August 21, 1997)

Some information about potential participants' characteristics of this was collected via the screener during the recruiting process. Other information about age, education, household income, marital status, and number of children under 18 living at home was requested at the end of the group.

1.4 Conducting the Groups

At the beginning of each group, the moderator briefly reviewed the purpose of the discussion and other guidelines to help put the participants at ease about how the group would work. The moderator then asked the participants to introduce themselves and briefly describe how long they had known or thought that they had an ulcer.

Next, the participants discussed their experiences with ulcers, describing various effects of ulcers on the lifestyle and dietary habits, as well as different treatments they had tried. Following this, participants reviewed a set of brief scientific statements about *H. pylori* and treatment to cure ulcers. These statements included:

- Most ulcers are caused by an infectious agent.
- Nine out of 10 ulcers are caused by a bacterium, not stress or spicy foods.
- This bacterium is called *H. pylori*.
- These ulcers are usually cured with antibiotics.
- There are tests your doctor can give you to determine whether you have *H. pylori*.

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The remaining time was devoted to reviewing the four concepts. Prior to displaying the concepts, the moderator emphasized that the concepts should be viewed as preliminary ideas for communicating information about the science statements to people—not as finished posters or advertisements. The moderator stressed the importance of thinking about the concepts as starter ideas to help participants decide what words and pictures should be used when actual materials are developed.

The concepts were printed in color in a poster-sized format and introduced one at a time, in rotating order for each successive group.

1.5 Analysis

Focus groups facilitate indepth examination of complex issues by providing a flexible tool for exploring participant awareness, attitudes and beliefs, behavior, motivation, intentions, and concerns relative to particular topics. Focus group findings are qualitative, not quantitative. As such, the value of focus group findings is dependent on researchers examining results systematically. Furthermore, the procedures used to analyze focus group results are not standardized, which heightens the importance of addressing the data systematically.

The process used to analyze this series of focus groups is based on that recommended by Krueger (1994). Krueger emphasized that analysis of results must be systematic and verifiable. He recommended processing each group briefly at its conclusion, then developing a total picture of all of the groups, and finally considering particular groups and responses to specific questions.

In analyzing the data, the Westat research team sought common themes, points of interest, and tendencies among participant comments by observing the following:

- **Step 1.** Once all 12 groups were completed, the available data were compiled, including observer notes, audiotapes, group summaries prepared by each of the three moderators for his/her respective groups, transcripts, and information about the participants' backgrounds. All data were initially examined at once in order to absorb a complete overview and to begin noting potential trends and patterns for further examination. This activity was conducted by one member of the research team and then subsequently examined by two others.
- **Step 2.** Following this primary overall assessment, the findings from each *group* were more closely considered one at a time. During this stage of analysis, findings from each group were examined to discern how they reflected, differed from, or added to tentative observations made during Step 1. This secondary,

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close examination of individual groups was designed to continue the overview process while adding more in-depth analysis.

- **Step 3.** The third step in analyzing these group findings was to consider the information one *topic* and *concept* at a time. Conclusions drawn from scrutinizing the findings on each discussion topic across the groups were compiled and compared. Quotes that highlighted the discussion were extracted from notes and transcripts and used to illustrate points. Additionally, the research project manager who observed six of the groups but was not involved in preparing the initial draft of the report, examined the conclusions.
- **Step 4.** The final task was to examine the conclusions drawn from the findings in terms of practical implications.

2. Discussion of Findings

The following findings emerged from the 12 focus groups.

2.1 Life With Ulcers: Life with ulcers involves significant pain for many sufferers as well as inconvenient lifestyle adjustments. Chief among lifestyle effects is changing one's diet to forego foods believed to cause and/or aggravate ulcers—especially spicy foods.

Participants made clear that living with ulcers involves pain and discomfort that call for unwelcome lifestyle adjustments, especially where diet is concerned. Participants in most groups said that ulcers are a significant problem except in the Hispanic groups where participants were more likely to indicate that they have learned to adapt, so that ulcers are not a major problem. In one of the Hispanic men's groups, however, some participants thought their ulcers would kill them or turn into cancer.

Avoiding spicy foods to control ulcers was mentioned in all 12 groups. Among African American and Hispanic groups, avoiding fatty or greasy foods was also common. For example, African American participants talked about missing fried chicken, hot sauce, and hot wings. Hispanic participants noted how inconvenient it is to avoid many of their favorite ethnic foods such as jalapeno peppers, carnitas and other popular dishes. Non-Hispanic white participants were often mentioned avoiding caffeine. In most groups, participants also mentioned having to avoid alcoholic beverages.

Other foods people talked about *avoiding* included:

- Dairy and processed foods;
- Pasta and tomato sauce;
- Fast food;
- Mexican food (not just in Hispanic groups);
- Crab soup;
- Pizza;
- Pork; and
- Red meat.

Foods they try to eat *more* of to help control ulcers included:

- Broiled foods (instead of fried);
- Vegetables and fresh fruit;
- Cream-based soups; and

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- Salads.

Participants also talked about other effects that their ulcers have had and accommodations they must make. For example:

- Eating small meals;
- Eating early in the day;
- Taking medications all the time;
- Difficulty sleeping;
- Not know when a flare-up will occur;
- Fearing what will happen if one does not adhere to dietary restrictions; and
- Being angry, depressed, irritable with family (Hispanic men).

2.2 Use of Medications: Life with ulcers requires regular use of medications to relieve symptoms. Almost all participants reported use of common over-the-counter medications such as Tagamet, Zantac, PepcidAC, Tums, Maalox, AlkaSeltzer, and Mylanta. Only a few people reported taking any prescription medications for ulcer relief; two of these reported being treated with antibiotics.

Almost all participants were taking some kind of over-the-counter medication to relieve ulcer symptoms. Almost none of the participants, including those whose ulcers were diagnosed by a physician, were taking prescription medications. One exception was Prilosec (“*the purple pill*”), which was mentioned in two groups (both non-Hispanic white) by a few people. In addition, antibiotics were mentioned in two groups (one non-Hispanic white and one with Hispanic women). A non-Hispanic white woman identified her prescription as “Flagyl and Biaxin.”

2.3 Other Remedies: Home remedies and homeopathic treatment were mentioned often among the Hispanic participants and sometimes among African American participants. These remedies were seldom mentioned by any non-Hispanic white participants.

Participants in the African American and Hispanic groups were specifically asked if they use any home or folk remedies. In response to this question, several people reported that they do, especially among the Hispanic participants. In every one of the four groups with Hispanic participants, people reported using remedies such as:

- *Nopales* (cactus);
- *Sabila*;
- Herbal teas such as *te de milagros*, *te de manzanilla*, *te de yerba buena* and *te de istafiate*;

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- *Buscapina*;
- *Compuesta*;
- *Aquq de metamote*; and
- Papaya pills.

In the African American groups, the following were mentioned:

- Baking soda in water;
- Flour in water;
- Warm water;
- Warm orange juice;
- Baking soda in water;
- Goat's milk;
- Mustard; and
- Herbal teas.

The one woman who said she uses herbal teas indicated that they have cured her ulcers. This sparked strong interest from the other participants in her group.

2.4 Cause of Ulcers: Almost everyone in all the groups thought that ulcers are caused by foods and beverages and/or by stress. They said stress from work, family life, or other pressures causes flare-ups that can only be controlled by avoiding certain foods and using medications and/or home remedies. A few people had heard about the *H. pylori* finding before the moderator brought it up. One person thought ulcers were caused by taking too much aspirin.

Most participants believed that their ulcers were caused by food—especially spicy or fatty foods—or stress. Alcohol was the third most frequently named. A few people mentioned having heard about a bacterium and some could name it. One of the people who had heard about the bacterium said it was associated with roaches. This, he explained is the reason so many African Americans have ulcers, because they live in poor housing. Other causes cited by at least one person were:

- Excessive use of aspirin;
- Skipping meals;
- Not drinking enough fluids;
- Taking medications on an empty stomach;
- Anger;
- Smoking; and
- New cultural habits that bring longer work days (only in a Hispanic group).

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- 2.5 Awareness of Bacteria Theory:** A few people had heard or read that a bacterium causes ulcers, including some people who named *H. pylori* when they described what they had heard or read. Almost everyone who knew about the bacterium had learned about it from consumer media, medical literature, or the Internet — *not a physician.*

At least one person in 8 of the 12 groups had read or heard something about the bacteria; a few could even name it and recall hearing that “90 percent ulcers are probably caused by this bacteria.” The four groups in which no one had heard about it included one non-Hispanic white group, one African American group, and two Hispanic groups. Some of those who had heard about it reported to their groups:

Ulcers are a bacteria and are easy to get rid of.

Some Austrian doctor came up with the theory.

A microorganism is responsible for 85 percent of ulcers...the British established this as a fact 10 to 15 years ago. We've been slow to accept this in the U.S.

Most people who knew anything thought they had read or heard about it in consumer media (newspapers or television) or medical literature, such as the *New England Journal of Medicine*. **Very few had heard about it from their doctors.** As one woman who had read about the bacterium put it:

My doctor's never suggested it so I've never gone after it.

- 2.6 Diagnosis for H. Pylori:** There were only five participants who said they had been tested for *H. pylori*. Four of these were in the non-Hispanic white groups; one in a group with Hispanic women. One was treated with “Flagyl and Biaxin” and one with “antibiotics.” Another had just been diagnosed but no treatment was prescribed yet. Two tested negative for it.

Two women, one a non-Hispanic white and a Hispanic, said they were or had been treated with antibiotics. One had taken Flagyl and Biaxin, but the Flagyl had caused a yeast infection so she stopped the treatment and resumed taking Zantac.

Two other non-Hispanic white participants said they had tested negative for the bacterium. One explained to his group:

I know there's a blood test for it because I don't have H. pylori or whatever it is...They did a blood test and that's not the cause of my problem.

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The other participant who had also tested negative for the bacterium, said she was not sure if the test was sensitive enough and planned to ask her doctor to treat her with antibiotics anyway.

2.7 Response to Science Statements: Most people were excited to hear that there is a now cure for most ulcers. Life without ulcers would be great: no pain, no medications, and no dietary restrictions. Several people thought they would contact their doctors after learning this information in the focus group. However, several people were very skeptical about the information. *They could not believe it was true if they had not heard about it already from their doctors.*

Following the general discussion about life with ulcers and participants' beliefs about what causes them, the moderator read and displayed a series of "science statements" about ulcers. These statements were:

- *Most ulcers are caused by an infectious agent.*
- *N out of 10 ulcers are caused by a bacterium, not stress or spicy foods.*
- *This bacterium is called H. pylori.*
- *These ulcers are usually cured with antibiotics.*
- *There are tests your doctor can give you to determine whether you have H. pylori.*

Most people were excited to hear that a cure has been found for ulcers. In some groups, participants wrote down the science statements to take home with them. A cure would make them happy, relieve their pain, alleviate fear of stress, eliminate medications, and allow them to eat foods they miss and to drink alcoholic beverages. Most participants believed that the information was true, but several also believed that food and stress must play some kind of role.

Questions evoked by the science statements included:

How do you contract the bacteria and can it be prevented?

How long do you take the antibiotics? (with concern about recent news regarding overuse of antibiotics)

How did they discover it?

How sensitive is the test?

Is the cure permanent?

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Why don't doctors mention the test?

If a bacterium causes ulcers in 9 out of 10 people, what is the cause for the 10th?

How many different kinds of antibiotics are there to cure this?

Once cured, can ulcers still recur?

What does the 'H' stand for?

A participant in the group where this last question was asked said he had recently been diagnosed and had done a Web search that enabled him to correctly tell everyone that the 'H' stands for *helicobacter*.

Some participants (mostly men) in several groups were very skeptical and/or upset that they had not heard about this already. For example:

How many years has this information been out?

Why hasn't my doctor told me about this?

That is garbage.

This is contrary to everything we've heard so far.

It's hard to believe.

You can cure it now?

If there was a cure for it, we would know about it by now.

- 2.8. Comparison of the Concepts:** “Good News” was chosen by participants in 10 of the 12 groups as either the first choice or as tied for first with another concept. The focus on “cure” in “Good News” was more compelling than the focus on misconceptions about the cause of ulcers featured in “Goodbye Ulcers” and “Not What You Thought.” The uplifting tone was more appealing than “Sadie” and “Eloise.”

Alerting people to the fact that ulcers can be cured was very important. “Don’t just control it” was news that participants thought people should get in any concept that is developed. “Good News” accomplishes this goal better than the other concepts.

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However, there was lingering interest in the idea of communicating that ulcers are not caused by diet or stress. The participants who did not choose “Good News” liked learning from “Goodbye Ulcers” and “Not What You Thought” that perhaps they could enjoy favorite foods again or stop fearing a flare-up when something stressful happens.

There were reservations about using the word “forever.” Participants were concerned that this would be difficult to believe and might make people more skeptical about the overall message of a cure being available.

Participants in several of the non-Hispanic white and African American groups thought that the “Sadie” concept could be eliminated from consideration. A few women in one Hispanic group chose “Eloise” as their favorite.

Every group reviewed four concepts. The concepts were introduced and discussed one at a time in rotating order across the series of groups. For the Hispanic groups, the concepts were translated and adapted to be more culturally appropriate. For example, one of the original concepts displayed for the non-Hispanic white and African American groups was called “Sadie” and features an older woman. This concept was re-titled “Eloise.”

Participants were drawn to words like “cure” and “ask your doctor” and almost always commented critically about their absence from some of the concepts. They also seemed to prefer the features showing people and foods, which depict the pleasures of life without ulcers. However, participants also seemed to be more confused about the intended meaning of these two concepts. They often interpreted the people in the picture as ulcer patients, not as people who may be sources of stress.

“Good News” was favored by some participants because the image of the newsboy and newspaper conveys how important this discovery is.

In most groups, “Sadie” was definitely ranked last, even though some participants thought she was amusing and attention getting. For the most part, participants felt strongly that people in the concepts should exemplify how improved life without ulcers would be; Sadie’s expression made it look like she had not been cured. “Eloise” fared better among Hispanic participants; they liked her, but generally did not choose her as the most favored concept.

2.9 “Good News”: This concept was chosen as “the best” in 8 of the 12 groups and tied for best in 2 others. The prominence of words such as “cure” and the “news” image communicated that there has been an important breakthrough in ulcer treatment. This concept did not tell people to “Ask Your Doctor,” which participants noticed and recommended including. One important concern came up in both the African

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American and Hispanic groups: many people associated the word “infection” with serious, contagious illnesses and were alarmed by the association between ulcers and “infection.”

2.9.1 Main Idea/First Reactions

Participants in most groups responded very favorably to this concept. The main idea that there is a cure for ulcers now was uplifting to people who are beleaguered by what has been involved in controlling their ulcers. Comments included:

This lifts your spirits.

I would be excited [if I saw this]...I would think, Great. I'm, going to call my doctor right away and find out what this infection is and does it affect me?

The point is that ulcers are caused by an infection, not diet or stress.

The concept is powerful because it means I am saved.

I've always been under the impression that it's something you live with, that you control. They're saying 'cure.' That's great.

2.9.2 Target Audience for “Good News”

Most participants thought this concept approach was aimed at ulcer patients. A few also thought it was aimed at doctors.

2.9.3 Motivational Effect of “Good News”

Many participants in most groups said this concept would motivate them to call their doctor. The concept that there is a cure was more prominent in this concept than in others that also used the word “cure.” As two participants put it:

This has enough information to make me ask my doctor.

If we look at the whole picture, it makes sense. It would motivate me to get more information.

2.9.4 Strengths of “Good News”

Participants in most groups cared much more about “cure” than about “cause.” In general, very few people thought that wording about an “infection” was an asset although there

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were a few participants in non-Hispanic white groups who thought this was important to highlight. Other participants thought “infection” was alarming. Main points include:

The message is in the picture, which more people are likely to look at than to read the words.

The question “How can an infection be Good News?” would be intriguing enough to read the rest of the information.

The headline of a newspaper is an appropriate visual for communicating the importance of the discovery of a cure.

The joyful mood and enthusiasm of the newsboy is an asset.

“Aliviese para siempre” is a powerful, credible statement (for Hispanic participants).

2.9.5 Concerns/confusion about “Good News”

To many, infection means something invisible in the body; some participants in Hispanic groups associated the word with cancer or deadly illness.

Infection is dangerous and refers to an incurable and/or transmittable disease such as AIDS or cancer:

With the word infection, I think of AIDS. I do not think of ulcers until I read the small print.

Bacteria can wash off; infection can't.

“Cure *forever*” is hard to believe:

Cure it forever over-promises and would be more believable as could cure it forever.

The concept does not say, “See your doctor.”

A cartoon image may not be serious enough for the topic; ulcers are not funny.

People may not read the print on the newspaper, which is where the main message is.

Among Hispanic participants, a few said that “descubren cura” (discover a cure) was

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unclear and suggested a more descriptive statement such as “discovery of a marvelous medicine that cures ulcers.”

2.9.6 Suggestions From Participants About “Good News”

Make the word “cure” more prominent.

Make the point in the visual *and* the words.

Use the word “bacteria” instead of “infection” and explain that it causes ulcers.

“Ulcer” needs to be more prominent than “infection.”

Add information including “call your doctor.”

Add an 800 number or Website.

Address how the infection causes ulcers.

Address where the bacteria comes from.

Add to “see your doctor” the words “for the blood test” to show that the infection can be diagnosed with an easy test.

Let all the doctors know:

If [the cure] is so great, why aren't they calling all their ulcer patients and saying, 'I've got news.'

Why is the focus strictly on the public, not the doctor?

2.10 Response to “Goodbye Ulcers, Hello Life”: Participants liked the idea that they could be cured and once again enjoy life in ways that they cannot while contending with ulcers. However, they were sometimes confused about how the visual components -- portraying people associated with stress or food—connected to the message. Many of their recommendations about this concept seemed to suggest that they thought the characters were patients or, if not, that the characters should be patients exemplifying how good life could be if they could say goodbye to ulcers.

2.10.1 Main Idea/First Reactions

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Most people understood the intended idea of this concept: you do not have to live with ulcers and should ask your doctor about the cure. For example:

You can have your life back and not be affected by people that might stress you out, foods that might upset your stomach. It's very catchy.

You can feel good again.

Life can have a new beginning.

2.10.2 Target Audience for “Goodbye Ulcers, Hello Life”

Most people thought this was aimed at ulcer patients like themselves and that it would draw their attention:

[This is for] anyone who takes Maalox.

[This is for] ulcer patients who thought ulcers are caused by stress.

One participant thought this was aimed at doctors.

2.10.3 Motivational Effect of “Goodbye Ulcers”

Quite a few participants thought this would motivate them to ask their doctor about a cure for their ulcers:

It would make me think and talk to my doctor about it.

One participant said she would call CDC.

2.10.4 Strengths of the “Goodbye Ulcers” Concept

Participants identified the following as strengths of this concept:

The people look happy: “It has smiling faces.”

The picture of food suggests that you can go back to pre-ulcer eating.

It reflects scientific data well and would be motivational.

“Relief” and “Help” are attention getting.

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“Goodbye” is eye-catching.

“Seeing the doctor for a cure” is important.

It gets the message across with minimum of words — like a billboard.

It’s colorful.

It shows everyday people: “The people are just folks, not all beautiful people and there’s a multi-racial component.”

The cartoon approach is appealing.

It celebrates that you can now eat what you want and “bad people aren’t going to be bothersome anymore.” (Hispanic group)

2.10.5 Concerns/Confusion about “Goodbye Ulcers”

Among the non-Hispanic white and African American participants, there were some concerns and indications of some confusion about who is depicted in the pictures. However, these were not major. Hispanic participants had more significant concerns about the “cure” phrase in the Spanish copy and about the visual images used. Participants in all of the Hispanic groups recommended significant changes to the visuals. The following summarizes concerns or confusion voiced by participants:

From the non-Hispanic white and African American groups:

It may imply that the people in the picture *do* cause ulcers.

People in the picture *have* ulcers; the point is to demonstrate that anyone can have an ulcer.

It is offensive to show the African American in an occupation (chef) that serves others. (This comment was in an African American group, but another participant said that he would not look at it as a race thing. Yet another said “The words are important. I don’t even focus on the picture.”)

This will not be relevant to people without a mother-in-law, boss, or chef.

People will interpret the concept as a pharmaceutical ad.

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It should not depict only people as a cause of stress.

“Cure for life” is too strong:

How can any doctor guarantee anything for life?

The picture is too busy:

It's cluttered and I would flip by it.

From the Hispanic groups:

“Una cura que dura” was ambiguous and created confusion about a permanent cure: change to “una cura permanente” a statement.

2.10.6 Suggestions From Participants About “Goodbye Ulcers”:

From the non-Hispanic white and African American groups:

Add more copy and information about what to ask the doctor.

Add information on the availability of a test and information on ulcers being caused by an infection to prevent reinforcing that stress causes ulcers: “[As is] it leaves it at what I always thought” and “The excitement I see here tonight is the fact that it’s an infection...”

Refer to common myths in the *wording*, not just in the pictures.

Include someplace to call or write.

Mention that there is a simple test: “If it’s as simple as a blood test, that’s simple to me.”

Change the chef to examples of food that people associate with ulcers.

Use the word “cure” more prominently.

Make the food identifiable if it is supposed to be what people associate with ulcers.

Use other examples of stress: balancing a checkbook, a picture of children.

Add Coke, Pepsi or alcoholic drinks.

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Add people to the background who are having a party and enjoying themselves.

From the Hispanic groups:

Note that Hispanic participants suggested even more strongly that visual elements in the concept should depict *people enjoying life*. In contrast, some of the non-Hispanic white and African American participants advocated depicting more examples of *stressful* things that people associate with ulcers. For example, Hispanic participants said:

The characters should depict happy tranquil people and families participating pain free in family events and parties or other celebrations; e.g., dancing at parties; embracing and leaving on a trip; children singing; people eating Mexican food (spicy, fatty Mexican foods like jalapenos, carnitas);

show beer; mariachis and other Latin music to convey a celebration; or

show a beach or fair.

Other suggestions from the Hispanic groups included:

This could also show a doctor informing patients about Good News.

Show younger people to appeal more to younger Hispanic ulcer sufferers.

- 2.11 “Ulcers: Not What You Thought”: Participants understood the main idea of the concept to be that ulcers are not caused by what they had believed but there were frequent suggestions to depict examples of what people associate with ulcers (i.e., different spicy foods and stressful situations). In addition, participants thought this concept did not focus enough on the fact that there is a “Cure” and they felt that this diminished its appeal and effect.**

2.11.1 Main Idea/First Reactions

Most people understood the main idea of this concept to be that ulcers are not caused by stress, spicy foods, or something you do to yourself. One thought the main purpose was to get people to “ask your doctor” about the cause.

Opinions of the concept were mixed. In some groups, participants liked it very much. Others responded neutrally. In one African American group, the depiction of the African American character in a uniformed occupation was offensive again (as it had been in “Goodbye Ulcers.” There also seemed to be some confusion about what the people were supposed to

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represent—people who cause stress, or people who have ulcers. There were numerous suggestions about showing *situations* that cause stress, instead of people, and changing the wording to “What’s to blame?”

2.11.2 Target Audience for “Not What You Thought”

Most participants thought this approach was aimed at people with ulcers. In groups where participants had already seen other concepts, some people thought this concept was directed to ulcer patients more clearly than others.

2.11.3 Motivational Effect of “Not What You Thought”

Quite a few people thought this might motivate them to call their doctor, but others said that confusion about the visual images would diminish the motivational effect. Positive comments about the motivational quality of this concept included:

I would want to find out what does cause ulcers if it isn’t stress.

This contradicts what I thought [about the cause of ulcers] so it makes me want to read further.

2.11.4 Strengths of “Not What You Thought”

The CDC logo:

The ‘Centers for Disease Control’ logo. I’d be more suspicious if it said Pfizer or some drug company. CDC has more credibility...more public-spirited.

Starting out with the word “ulcers” grabs attention from ulcer sufferers.

The humorous approach is an asset.

It tells you that you might have been doing the wrong thing about ulcers and should see a doctor; maybe there is something else you should find out.

The mix of people gives everyone someone they can relate to.

2.11.5 Concerns/Confusion About “Not What You Thought”

The concept is confusing without more words to explain what it means; e.g., it does not tell what causes ulcers.

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No one is smiling.

The concept is not serious enough.

The idea that it is just people who cause stress.

People think it is food that causes ulcers, not chefs.

People might panic about “infectious disease” but that might make them go to the doctor.

2.11.6 Suggestions From Participants About “Not What You Thought”

From the non-Hispanic white and African American groups:

Discard “*Who’s to blame?*” and substitute “*What’s to blame?*” Reflect *situations*, not people, that cause stress; e.g., stacks of bills or traffic.

Add something about ulcers being a disease “so it doesn’t leave people hanging.”

Say “It’s now curable. See your doctor.”

Clarify the main idea by adding information about “not treating symptoms such as stress, food, etc.”

Add information about getting a check-up.

Change the occupation of the African American to a professional one.

Add an 800 number or Web address.

Add words that say, “It’s not your family, not your boss, not the food you eat” so that there is no mistake about the message.

Make the characters smile; they don’t look happy.

Make the picture of spicy food clearer.

Add children to depict the stress of family obligations.

Include smoking and alcohol as examples of what people believe causes ulcers.

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From the Hispanic groups:

The tagline about consulting a doctor would be more compelling if it said more; e.g., “Ask your doctor about the cause of ulcers.”

State “las ulceras no son causadas por lo que pensaba” (“Ulcers are not caused by what you think.”) Change the last sentence to: “preguntenle al medico que es la causa.” (Ask your doctor what is the cause.)

Increase the size of “Ask your physician” and make it bolder.

Depict common targets of blame: day-to-day pressures like traffic, spicy foods, alcoholic husbands, financial pressures, medications, family problems; and discrimination.

- 2.12 “Sadie” / “Eloise”: “Sadie” was the least popular of the English concepts among non-Hispanic white and African American participants. Although some people thought she was amusing and attention-getting, there were strong concerns about how her dour expression contradicted the message that there is a cure for ulcers. Participants expected to see someone who has been cured of ulcers looking happy and enjoying life. Some of the Hispanic participants liked “Eloise” and could relate well to her complaining about ulcers, but “Eloise” was seldom chosen as the best concept.**

2.12.1 Main Idea/First Reactions

Reaction to “Sadie” was generally negative in all but one of the non-Hispanic white and African American groups regardless of the order in which concepts were displayed. Participants usually laughed when “Sadie” was displayed and some said she was attention-getting and amusing but even those participants who liked her did not think she was a good image for the message. However, participants generally understood the intended idea that there is a cure for ulcers that can provide relief and many related to the idea that ulcers make you complain.

Hispanic participants generally liked “Eloise”, an adapted and translated version of “Sadie.” They said the message was a credible, hopeful one about doing something positive in your life. (But few chose the concept as the “best” among the four.)

2.12.2 Target Audience for “Sadie”

It was common for participants to say that this concept appeared to be aimed at families and friends of ulcer patients who are tired of hearing complaints. Participant seldom thought that

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this was aimed at ulcer sufferers themselves. For example, participants said:

[The only patients who would relate to this] are people who enjoy talking about their pain or hypochondriacs.

It's not talking to me.

(The target audience for “Eloise” was not specifically addressed by the Hispanic participants.)

2.12.3 Motivational Effect of “Sadie”

Very few people in the non-Hispanic white and African American groups said they would be motivated to do anything in response to the “Sadie” concept unless it contained both a more upbeat visual and more information about seeing your doctor about *new* research and a drug to cure ulcers.

Hispanic participants did think “Eloise” was motivating because it “invited them to take an active role in their treatment.”

2.12.4 Strengths of “Sadie”/ “Eloise”

From the non-Hispanic white and African American groups:

Sadie is funny and draws attention:

She makes you smile.

“Start the cure” would alert you that there is one.

It introduces the idea that there is a cure.

The words “ulcer” and “cure” draw attention.

From the Hispanic groups:

“Eloise” is powerful because it invites action.

People can identify with her complaints about ulcers.

2.12.5 Concerns/Confusion about “Sadie”

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Most of the concerns raised about “Sadie” focused on how unhappy she looks, as if the cure did not work for her. Participants noted:

Sadie seems to be a hypochondriac, which could make people think that ulcers are not serious.

Sadie is a negative image without a “before” and “after” version to show the positive change in her.

The “miserable” image is incongruent with message.

Unhappy face confused the concept and instilled doubt about and mistrust of the message about treatment.

Comments included:

Ulcers were not the only thing that’s wrong in that lady’s life.

She looks depressed.

If her ulcers were cured, her attitude would change.

She should be smiling. She looks like she still has an ulcer.

She’s too old and glum. Make her 20-30 years younger.

If she’s ulcer-free, why is she sad?

From the Hispanic groups:

No concerns or confusion were reported about “Eloise.”

2.12.6 Suggestions from participants about “Sadie”/ “Eloise”:

Use before and after pictures to show someone who is happy he/she has been cured.
(From most groups, including the Hispanic ones.)

Add more information to reflect some of the scientific data to clarify the message claims.

Tell what action to take.

Add a phone number or Internet contact.

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Make the word “cure” more prominent.

Emphasize that this is “new” information.

Show a picture of an ulcer.

Add information about how someone gets *H. pylori*.

Explain side effects of the cure.

2.13 Familiarity With CDC: There was little familiarity with “CDC,” especially outside Atlanta. However, once it was explained, most people felt that association with CDC would make the information more credible to people.

In four of the five cities—all but Atlanta—familiarity with what “CDC” stands for was limited. However, once it was explained, most participants thought this was a positive association and that the information would seem credible if it came from CDC. Some participants believed that even if people are unfamiliar with CDC, the words ““disease control” would make them think they could trust the message. Some people said they were much more likely to find the information believable than they would if it came from a drug company. Comments included:

If they [CDC] can cure, or at least stop, ebola, they ought to be able to find a cure for ulcers.

People have respect for CDC. I've called them for information. (This participant was in an Atlanta group.)

Recommendations about highlighting CDC included making the logo larger and spelling out what the letters stand for more prominently. A few people also suggested adding other, more familiar endorsements such as from the American Medical Association. In the one group held in Washington, DC, some participants advocated including the National Institutes of Health.

There were almost no concerns about CDC, including among African Americans, who were specifically asked if they thought they or other African Americans have any negative associations with CDC. One African American participant associated CDC with “transmittable” diseases and seemed to think that would not include ulcers. Another wondered if people would think that information coming from CDC is still tentative or on “trial” rather than proven.

2.14

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Channels for Communication: Participants in all groups recommended a range of channels -- such as print, broadcast, and transit media and print in community locations -- for communicating information about *H. pylori* and treatment for it. Specific examples of media and locations varied somewhat between non-Hispanic white, African American and Hispanic groups.

For example, “church bulletins” were mentioned only in Hispanic groups. The following lists participants’ suggestions:

Non-Hispanic white groups:

- Having doctors explain more about this to patients;
- Medical/science periodicals: “Anything in a medical or science magazine [would get my attention]”;
- 800 number to call for information;
- Print material in doctors’ offices; “more believable in the doctor’s office”;
- Bags that prescriptions come in: “When I fill a prescription, other medications are advertised on the bag. I read it; it’s a good way to get information out”;
- Coupons for discounts on the drugs used to cure ulcers;
- Consumer magazines;
- Bus ads;
- *Wall Street Journal*; and
- Drive time radio: “You may be more likely to listen, than to read ads.”

African American Groups

- Medical offices and professional buildings with health care services;
- Libraries;
- Senior citizen centers;
- Public transportation;
- Billboards;
- Grocery stores;
- Liquor stores;
- BET and United Paramount Network programming;
- Music video channels;
- Magazines (*Sports Illustrated*, *Golf*, *Car & Driver*, *Ebony*, *Essence*, *Jet* and health and fitness publications);
- Local newspapers;
- Website (strongly recommended); and
- Direct mail: (“Senior citizens read their mail.”)

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Hispanic Groups:

- Spanish language newspapers;
- Medical offices;
- Pharmacies;
- Hospitals and clinics;
- Health fairs;
- Spanish-language television;
- Church bulletins;
- Schools and children's recreation sites: "Children are educating parents these days on healthy lifestyle issues";
- Restaurants;
- Bars; and
- Airports.

Do not use direct mail: "People would throw it away."

3. Conclusions and Recommendations

The following are suggested by the findings from these focus groups.

1. A creative strategy that focuses on the fact that there is now a cure for ulcers that can relieve the pain and inconvenience of controlling them will be important. The actual cause is of much less interest and importance to people than the fact there is now a cure. While some reference to the cause will be essential to explaining the availability of a cure, caution is needed to avoid confusion evoked by words such as “infection” and “bacteria.”
2. The “Good News” was chosen by most participants as the “best” overall approach because of its focus on “news” about a “cure.” Emphasizing that the cure is based on *new* information about what really causes ulcers will help to address the potential barrier posed by firm, yet incorrect, beliefs that food and stress cause ulcers.
3. When misconceptions about the cause of ulcers are addressed, it is important to refer to or show specific examples of foods and stressful situations that people blame their ulcers on. Participants in these groups sometimes misunderstood the connection between the people shown in “Goodbye Ulcers” and “Not What You Thought” and their beliefs about the cause of ulcers.
4. Participants exhibited strong interest in seeing people “like themselves” who look as if their ulcers have been cured and they are enjoying life. For example, “Sadie”/ “Eloise” was criticized for portraying the character as if she actually still had an ulcer instead of as one would hope she would look—happy—if she was really cured. This desire to see people exemplifying life without ulcers seemed to lead participants to interpret characters shown in “Goodbye Ulcers” and “Not What You Thought” as former or current ulcer sufferers. Many of the suggestions about these two concepts were inconsistent with the fact that the characters were supposed to be examples of people thought to cause stress or to fix foods that are mistakenly believed to cause ulcers: bosses, mothers-in-law, chefs. “Make them look happy” was a frequent recommendation.
5. Prominent use of “Ask your doctor about the cause and cure for ulcers” is advisable for communication strategies. Participants noticed and criticized the absence of “ask your doctor” if it was missing. They wanted to people to know that they can get more information and a cure.
6. Spanish language materials will be important for communicating messages about *H. pylori* to a significant portion of the Hispanic population according to participants in

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these groups.

7. Low awareness of CDC calls for more prominent use of the logo with the letters spelled out and perhaps a sentence explaining what CDC is and does. When CDC was explained to participants, its sponsorship of the information was considered an asset and the information was considered more credible than when the message was mistakenly thought to be from a pharmaceutical firm.
8. Efforts to educate physicians about *H. pylori* in the communication program are vital. People expect to hear information like this from their physician and were skeptical about whether it was true because their doctors have not mentioned it.
9. A variety of communication channels other than physicians will also be important given that many people are self-diagnosing and that both physician-diagnosed and self-diagnosed ulcer patients are using over the counter medications. Many ulcer patients may hear about this only from non-physician sources; e.g., pharmacists and consumer media. Availability of an 800 number or well-publicized Website with information about the cause and new treatment for ulcers would be a good resource.

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